Original Article

The Meaning of Parenteral Hydration to Family Caregivers and Patients With Advanced Cancer Receiving Hospice Care

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Abstract

Context. In the U.S., patients with advanced cancer who are dehydrated or have decreased oral intake almost always receive parenteral hydration in acute care facilities but rarely in the hospice setting.

Objectives. To describe the meaning of hydration for terminally ill cancer patients in home hospice care and for their primary caregivers.

Methods. Phenomenological interviews were conducted at two time points with 85 patients and 84 caregivers enrolled in a randomized, double-blind, controlled trial examining the efficacy of parenteral hydration in patients with advanced cancer receiving hospice care in the southern U.S. Transcripts were analyzed hermeneutically by the interdisciplinary research team until consensus on the theme labels was reached.

Results. Patients and their family caregivers saw hydration as meaning hope and comfort. Hope was the view that hydration might prolong a life of dignity and enhance quality of life by reducing symptoms such as fatigue and increasing patients' alertness. Patients and caregivers also described hydration as improving patients' comfort by reducing pain; enhancing the effectiveness of pain medication; and nourishing the body, mind, and spirit.

Conclusion. These findings differ from traditional hospice beliefs that dehydration enhances patient comfort, given that patients and their families in the study viewed fluids as enhancing comfort, dignity, and quality of life. Discussion with patients and families about their preferences for hydration may help tailor care plans to meet specific patient needs. J Pain Symptom Manage 2012;43:855–865.

The first two authors (M. Z. C. and I. T. -V.) contributed equally and agreed to share responsibilities and credits for first authorship.

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Introduction

The controversy regarding whether to administer hydration during patients' last weeks of life has generated intense debate in the media and the medical literature for more than 20 years.[1–5] In some countries, such as the U.S., patients with advanced cancer who are dehydrated or have decreased oral intake almost always receive parenteral hydration in acute care facilities but almost never in the hospice setting.[6,7] These marked differences in practice patterns occur across practice settings in the U.S. and internationally. Indeed, reported frequencies of providing artificial hydration to cancer patients in the last week of life ranged from 10% to 88%.[8] However, what is less clear is if and/or how these divergent practice patterns are influenced by the preferences of patients and their families.

Central to the deliberations occurring across medical, ethical, and legal communities is the question of whether parenteral hydration at the end of life represents the medicalization of death and dying or the fulfillment of a basic human care/need and comfort to patients and their families. Among clinicians, ethicists, and the courts, parenteral hydration at the end of life has largely been understood as a medical treatment that patients or their proxies may choose based on the potential benefits and risks and the religious and cultural beliefs of the patients or proxies.[9] However, patients and family caregivers may attribute a much different meaning and value to parenteral hydration and equate fluids to food, nurturing, love, warmth, compassion, caring, and comfort. Indeed, the limited number of studies assessing the attitudes of terminal patients and relatives regarding artificial hydration suggests that they tend to hold more positive attitudes toward hydration in the last week of life and often perceive it as clinically useful standard care at the end of life.[10–13] Thus, understanding patient and family attitudes, beliefs, and preferences regarding difficult end-of-life decisions such as hydrating patients during their last weeks of life becomes central to providing optimal patient- and family-centered care.[14]

The controversy surrounding the potential benefits and disadvantages of parenteral hydration remains.[15] The arguments in favor and against parenteral hydration in terminally ill patients have been previously summarized.[12,16,17] Arguments in favor of parenteral hydration in advanced cancer patients are: dehydration can cause confusion, restlessness, and neuromuscular irritability; oral hydration is given to dying patients reporting thirst, and, therefore, parenteral hydration also should be administered; parenteral hydration is the minimum standard of care in the acute care setting, and withholding parenteral fluid from dying patients may result in withholding therapies from other compromised patient groups; and dying patients have poor quality of life. Therefore, parenteral hydration should be given to reduce dehydration-associated symptoms, resulting in improved comfort and quality of life. Arguments against parenteral hydration in patients with advanced cancer are: comatose patients do not experience symptom distress; less urine results in a reduced need to void or use catheters; dehydration results in less gastrointestinal fluid, nausea and vomiting, and respiratory tract problems, and in a decreased frequency and severity of edema and ascites; dehydration may act as a natural anesthetic for the central nervous system; and parenteral hydration is uncomfortable and limits patients' mobility.

A limited number of studies have been published that explore patient and caregiver beliefs concerning parenteral hydration. One Italian survey assessing cancer patients' and family members' perceptions of subcutaneous and intravenous modes of providing hydration at the end of life found that patients and caregivers alike believed that hydration improved both the quality of life and clinical well-being of patients. Both patients and caregivers expressed willingness to continue with parenteral